



Validating the Use of ICD-9 CM Codes To Evaluate Gestational Age and Birth Weight

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14. ABSTRACT The objective of this study was to determine the accuracy of International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) derived gestational age and birth weight data in the Department of Defense (DoD) Birth and Infant Health Registry (Registry). We compared Registry data and 1858 randomly selected birth records from 17 DoD hospitals (gold standard), with oversampling for infants with birth defects. We performed extraction of record information and matching subject data to Registry data to assess birth outcome agreement. Of the 1858 reviewed infant records, 1700 met inclusion criteria, with 1669 records successfully matched to the Registry for analyses. Despite small differences in parental demographics, our investigation revealed exceptional agreement for our primary outcomes: kappa of 0.83 for preterm and 0.87 for low weight births. Subgroup analyses revealed no significant differences in birth outcome agreement based on the presence of a birth defect, or military parent rank, race/ethnicity, and branch of military service. This study demonstrates that ICD-9-CM codes provide an accurate assessment of preterm and low weight birth outcomes captured in this large birth and infant health registry. These results strengthen data integrity evidence for investigators examining parental occupational exposures and birth outcomes among service member families.						
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Validating the Use of ICD-9-CM Codes to Evaluate Gestational Age and Birth Weight

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Abstract: **Background:** Efforts to reduce preterm and low-weight births are among the leading public health objectives in the United States and the world. A necessary component of any public health endeavor is surveillance. The Department of Defense (DoD) Birth and Infant Health Registry (Registry) uses electronic healthcare utilization data to assess reproductive health outcomes among military families. Infant health outcomes are coded using the International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM). The objective of this study was to determine the accuracy of using electronically derived ICD-9-CM codes for assessing gestational age and birth weight among Registry infants compared to medical records. **Methods:** The authors assessed birth outcome agreement by comparing electronic Registry data for infants born at military treatment facilities (MTFs) from 1999-2002 and 1,858 randomly selected birth medical records from 17 MTFs, with descriptive statistics and measures of agreement, including the kappa statistic. **Results:** Of the 1,858 reviewed infant records, 1,669 were successfully matched to the Registry analytic dataset for analyses. Despite small differences in parental demographics, this investigation established "near perfect" agreement for the primary outcomes: kappa of 0.83 for preterm and 0.87 for low birth weight. Subgroup analyses revealed no significant differences in gestational age and birth-weight agreement based on the presence of a birth defect, military parent rank, branch of military service, or specific hospital characteristics. **Conclusions:** Electronically derived ICD-9-CM codes provide an accurate assessment of the gestational age and low birth weight reflected in the birth medical records of infants in a large birth and infant health registry. These findings support the integrity of Registry data for investigations assessing preterm and low-weight births among U.S. service member families.

Key words: birth registry, data validation, estimated gestational age, preterm birth, birth weight

Introduction

Preterm and low birth weight infants are at high risk for neonatal death and long-term health consequences compared with full-term and normal-weight infants. In the United States, 12.8% of infants are born preterm, defined as less than 37 completed weeks of gestation at birth, and 22.4% of all infant deaths are related to preterm birth. Almost 70% of infant deaths occur among the 8.1% of infants of low birth weight, or less than 2500 grams at delivery.¹⁻⁵ Among the many sequelae that disproportionately afflict preterm infants are neurodevelopmental impairments, with approximately 75% of cerebral palsy cases associated with early births.^{6,7} As gestational age and birth weight increase, health complications associated with preterm birth decrease; however, even near-term (late preterm) infants (≥ 34 to < 37 weeks estimated gestational age [EGA]) are at risk for health problems, including school-age developmental delays and disabilities.⁸⁻¹³ In 2005, an estimated \$26 billion was spent providing health care in the United States to infants born preterm.^{10,14}

Given their enormous societal burden, efforts to reduce preterm and low-weight births are leading public health

objectives in the United States and the world.^{10,15-17} A necessary component of any public health endeavor is surveillance. For the US military, assessing parental occupational exposures and reproductive health outcomes is a primary undertaking of the Department of Defense (DoD) Birth and Infant Health Registry (Registry), maintained at the Deployment Health Research Department at the Naval Health Research Center. The Registry was established in 1998 in recognition of the need to monitor the reproductive health of military families.^{18,19} The Registry captures electronic International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) codes and other health data from several databases on infants from birth to 1 year of life. To date, Registry researchers have conducted a number of investigational and analytical protocols focused primarily on birth defects, although preterm birth has also been assessed and found to range from 7.1% to 7.6%.²⁰⁻²² The objectives of this study were to assess the accuracy of ICD-9-CM codes to identify subcategories of preterm and low birth weight outcomes captured in this large birth and infant health registry compared with medical records from which the Registry data was derived.

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Methods

Population and Data Sources

The Department of Defense (DoD) Birth and Infant Health Registry was established in 1998 to increase the understanding of the reproductive health effects of military service by providing systematic surveillance of DoD beneficiary births and scientifically rigorous research of infant health outcomes. Data sources for the Registry include the Defense Manpower Data Center (DMDC) and the Defense Enrollment Eligibility Reporting System (DEERS), the central sources for personnel data for the DoD community. Military Health System Data Repository (MDR) data, also captured in the Registry, contains healthcare utilization data based on International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) coding for inpatient and outpatient care received at military treatment facilities (MTF) and civilian facilities. These electronic data sources allow the Registry to define live births and infant health outcomes through the first year of life among the approximately 100,000 infants born to military families each year.

Infant data are linked to the military parent's (sponsor's) demographic data including age, race/ethnicity, sex, educational attainment, service branch, rank, and marital status. The Registry captured over 300,000 infant births from years 1999 to 2002, with approximately 60% of these births occurring in MTFs, and the remainder occurring in civilian medical facilities.^{18-20,23} Infants are excluded from the Registry analytic database if data cannot be reliably linked to subsequent healthcare encounters. An example is same-sex multiples, who are excluded due to the inability to consistently differentiate their initial health care prior to the assignment of a unique medical identifier. Exclusion would also occur if changes in identifying information after the infant's birth do not match information in the DEERS; or if for any reason DoD medical benefits are discontinued shortly after birth, such as when a military parent leaves the service before the infant's DEERS registration.

Due to the difficulty in obtaining medical records from civilian facilities, infant birth records were limited to infants born at MTFs from 1999-2002. The resulting medical records, hereafter referred to as the *validation sample*, included 1,858 copies of medical records, ranging from complete records to limited excerpts of care. Initially obtained to validate Registry birth defect data, the validation sample oversamples birth defects. The 17 MTFs from which the records were collected represent a stratified random sample of MTFs, selected to ensure a mix of large and small facilities in the United States and abroad from each branch of military service. The Registry team requested infant birth medical records from DoD electronic hospital birth lists for a given year though a stratified random selection, based on the presence or absence of a birth defect, without prior knowledge of whether the selected infant records were ultimately included in the Registry analytic file. Ten percent of birth defect records and up to 1% of non-birth defect records were requested from each facility. The comparison group included infants born at MTFs from

1999-2002 and captured in the DoD Birth and Infant Health Registry. For appropriate comparison, this data was limited to that contained in records from MTF care and excluded all care received at civilian facilities. This group is hereafter referred to as the *Registry sample*.

Outcomes

Gestational age and birth weight were defined using ICD-9-CM codes. 765.0x and 765.1x represent extreme preterm (<28 weeks and/or <1000 grams) and "other preterm infants," (≥28 weeks and <37 completed weeks EGA), respectively. Code 764.xx refers to slow fetal growth and malnutrition. For low birth weight, only the fifth digit on ICD-9-CM codes 764.xx and 765.xx was used, as the fourth digit does not specifically refer to birth weight. If an electronic record lacked any of the above-mentioned codes, full-term or normal birth weight was assumed. If multiple codes were listed, the code indicating the shortest EGA or lower birth weight was used. Of note, the code 765.2x (weeks of gestation) was introduced in fiscal year 2003 to indicate specific EGA ranges and only applies to infants born on or after October 1, 2002. A total of 109 infants in the validation sample were born after this date; however, only records for 4 of these infants used the new ICD-9-CM codes. These infants were retained in this analysis and classified to the appropriate category according to pre-fiscal year 2003 ICD-9-CM code criteria.

Data Extraction and Matching

Data extraction from validation sample records and matching of this information to Registry sample data was conducted May-December 2009. For this process, a data extraction sheet was generated and information collected from birth medical records, which included personal identifying information and demographic data (hospital identification number, military parent-sponsor Social Security number, name, sex, and date of birth), and other data of interest (eg, twin and higher order births, known perinatal death). EGA and birth-weight information were obtained from the infant medical record, specifically the newborn record data sheet/profile, clinical record, or admission/discharge notes, which include maternal information, labor and delivery data, transition period information, and a physical assessment of the infant at birth, throughout their hospital stay, and at discharge. After record extraction, EGA and birth-weight data were converted to their appropriate ICD-9-CM codes for comparisons with Registry sample data. Data accuracy was confirmed twice during manual extraction and again during entry into an electronic spreadsheet. Infant records were excluded from analyses if they lacked key demographic or EGA data or were otherwise excluded from the Registry analytic file.

Medical record data were matched to the Registry database in a three-step process. The first matched subjects from both sources of data with perfect matches for sex, date of birth, and military parent-sponsor Social Security number (which is present on infant records). The second was a re-examination of all non-perfect matching records to check for any transcription errors, followed by repeating

Table 1. Infant Characteristic Comparisons Between the Matched Validation Sample and the DoD Birth and Infant Health Registry, 1999–2002*

Characteristic	Sample (%)	Registry (%)	P-value
	n=1,656†	n=196,580	
Mother, military	23.9	22.1	0.069
Military parent race/ethnicity			
White	58.5	61.5	0.064
Black	21.3	19.7	
Hispanic	10.4	10.1	
Other	9.8	8.7	
Military parent rank			
Enlisted	86	81.9	<0.001
Officer	12.7	16.9	
Unknown	1.3	1.2	
Maternal age, years			
≤18	2.3	2.3	0.996
19–34	89.5	89.5	
≥35	8.2	8.2	
Maternal marital status			
Married	86.7	89.3	<0.001
Unmarried	10.9	8.0	
Unknown	2.4	2.8	
Military parent service branch			
Army	41.1	40.7	<0.001
Navy	38.9	25.3	
Air Force	8.3	20.5	
Marine Corps	9.5	11.5	
Coast Guard and other	2.2	2.0	
Infants with birth defects	22.7	3.3	<0.001
Infant sex			
Male	52.2	51.4	0.535
Female	47.8	48.6	

*Limited to births at military treatment facilities.

†Thirteen subjects lacked full parent information and therefore are not included in this table.

step 1. Third, lists were generated for all non-matching infants' records and compared with all possible records contained in the Registry with the same hospital of birth, and a near match on date of birth. From these lists, final matches between the 2 data sources were determined through positive name matches and minor differences in other variables, such as date of birth.

Statistical Analysis

Descriptive statistics and measures of agreement, including sensitivity, specificity, overall agreement, and the kappa statistic were used to compare the validation

and Registry samples for the outcome measures of interest. Subgroup analysis was conducted to determine if measures of agreement varied based on the presence of a birth defect, parental characteristics, and specific hospital factors. For the purposes of calculations, the information in the validation sample was assumed to be true ("gold standard"). Sensitivity was defined as the probability that, given a condition is present, a test will be positive. Specificity was defined as the probability that, given a condition is absent, a test will be negative. Percent agreement was calculated as the total number of infants classified to the same category from both the validation sample and the Registry sample, divided by the total number of infant records in the study. The kappa statistic measures agreement between data sources above what is expected from chance alone. A kappa statistic in the range 0.8–1.0 represents "near perfect" agreement, 0.6–0.8 "substantial" agreement, 0.4–0.6 "moderate" agreement, 0.2–0.4 "fair" agreement, and 0.2–0.0 "slight or poor" agreement.^{24–26} All statistical analyses were performed using SAS software, version 9.2 (SAS Institute, Inc., Cary, NC).

Results

The validation sample included 1,858 records. After removing 20 records that lacked specific birth information, 1,838 records remained in the validation sample for possible matching to the Registry sample. Among the remaining 1,838 records in the validation sample, 1,669 (90.8%) were successfully matched to a record in the Registry analytic database and were used for analyses. Among the 169 non-matching records, 151 records matched to a file containing records routinely excluded from the Registry analytic database and 18 remained unmatched, possibly due to changes in identifying information after the infants' births. Among the 169 unmatched validation records, there were 53 preterm infants and 47 low birth weight infants. Adjusting for the high rate of same-sex multiples among the infants in the non-analytic dataset, these rates are similar to rates for the 1,669 validation sample records ($P=0.86$ for preterm and $P=0.08$ for low-weight births).

Table 1 shows a comparison of parental demographic characteristics for validation sample infants and Registry births from 1999–2002 at MTFs. Although demographically similar, more parents of infants in the validation sample were enlisted rank (86.0% vs 81.9%), unmarried (10.9% vs 8.0%), in the Navy (38.9% vs 25.3%), and less likely to serve in the Marine Corps (9.5% vs 11.5%) or Air Force (8.3% vs 20.5%). A larger percentage of infants in the validation sample had birth defects (22.7% compared to 3.3%).

Table 2 shows measures of agreement and comparisons between the validation sample and Registry sample for EGA. Agreement was "substantial" and higher for all comparisons except for the extreme preterm outcome where agreement was "fair to moderate." Shown are 2 different cut points for preterm birth to illustrate how measures of agreement vary based on slight differences in possible research criteria in the 36th EGA week window (252–258 days). Additional analyses did not reveal differences in measures of agreement based on the presence or absence

Table 2. Gestational Age (GA) Agreement and Comparison Between Validation Sample and Registry Sample

GA (n=1669)	Validation Sample	Registry Sample	Number in Agreement	Percent Sensitivity	Percent Specificity	Percent Agreement	Kappa Statistic*	95% CI
Full-term								
≥37 weeks, ≥259 days	1484	1504	1467	98.9	80.0	96.8	0.83	0.78, 0.87
Preterm†								
<37 weeks, <259 days	185	165	148	80.0	98.9	96.8	0.83	0.78, 0.87
<36 weeks, <252 days	108	165	102	94.4	96.0	95.9	0.73	0.66, 0.79
Extremely preterm								
<28 weeks, <196 days	10	23	8	80.0	99.1	99	0.48	–
Validated GA Ranges								
GA Categories**	≥37 wks	<37 wks <259 d†	36 wks 252–258 d	35 wks 245–251 d	34 wks 238–244 d	32 to <34 wks 224–237 d	≥28 to <32 wks 196–223 d	<28 wks <196 d
VS, n=1669	1484	185	77	38	16	21	23	10
RS full-term, n=1504	1467	37	31	4	0	1	1	0
RS preterm, n=142	14	128	46	34	13	17	16	2
RS extreme preterm, n=23	3	20	0	0	3	3	6	8

GA = gestational age; CI = confidence interval; VS = validation sample; RS = registry sample; wks = weeks; d = days.

* $P < 0.0001$ for all kappa statistics, exact P-values computed for extremely preterm, 95% CI = 95% confidence interval for the kappa statistics, not included for extremely preterm due to small sample size.

†Preterm category is not mutually exclusive and includes all births occurring less than the defining gestational age, including those extremely preterm.

**Registry data from ICD-9-CM codes 765.0 ("extreme preterm infants, <1000 g and/or < 28 completed weeks") and 765.1 (other preterm infants, >28 and <37 weeks gestation); lack of these ICD-9-CM codes indicates a full-term birth.

of a birth defect: for preterm (<37 weeks, <259 days), the kappa statistic was 0.83 for infants both without and with a birth defect (95% confidence intervals: 0.77, 0.88, and 0.75, 0.91, respectively). Nor were there significant differences with changes in military parent rank, parent branch of military service, or hospital specific factors, including size and services (eg, larger medical centers with neonatal intensive care vs smaller community hospitals), or military branch of service running the medical facility (data not shown).

Also shown in Table 2 are EGA frequency counts for subjects matched in the validation sample and the Registry sample. The Registry misclassified full-term births by 1.15% (17/1,484); and fully 83.8% (31/37) of all false-negative preterm births were infants born between 36 and 37 weeks EGA (252–258 days). There was no difference in EGA misclassification rates based on the presence or absence of a birth defect ($P=0.37$). The Registry sample classified 23 infants as extreme preterm births compared with 10 in the validation sample. However, the ICD-9-CM code indicating extreme preterm birth (765.0) applies to infants "less than 1000 grams and/or 28 completed weeks," thus, using both criteria for weight and EGA, 5 additional infants in the validation sample can be included in this category. Three of the 23 infants categorized in the Registry sample as extreme preterm were noted to be full term on chart review.

Table 3 shows measures of agreement and compares birth-weight data in the validation sample with the Registry sample. Agreement between the data sources is "near perfect," as indicated by kappa statistic values. This table

also shows that ICD-9-CM fifth-digit codes corresponding to birth weight ranges are well populated in the Registry sample, with an overall accuracy of 98.1% (1,633/1,664). For this outcome, 0.26% of normal-weight births were misclassified and 96% (24/25) of false negatives were in the 2000–2499 gram category, or nearly normal weight. Of interest, there were 101 infants in the validation sample who were both preterm and low birth weight, out of 185 and 110, respectively (data not shown).

Discussion

The increased risk of death and long-term health complications associated with preterm birth and low birth weight makes it necessary to continue surveillance and research of these important outcomes. Although abstraction of medical records is the preferred method for assessing preterm and low-weight births, the size and scope of most surveillance programs make such an approach cost prohibitive and logistically impossible, as data extraction requires significant time and knowledge from medically experienced individuals, particularly when information is not readily available on medical summary (face) sheets.^{27–29} The DoD Birth and Infant Health Registry is a global monitoring and research program that relies on ICD-9-CM codes obtained from electronic data sources to assess a variety of reproductive health outcomes. These analyses demonstrate that the Registry is a reliable tool for assessing preterm birth and low birth weight in a large and geographically diverse population.

Table 3. Birth Weight Agreement and Comparison Between Validation Sample and the Registry Sample

Birth Weight, in grams (n = 1664)*	Validation Sample	Registry Sample	Number in Agreement	Percent Sensitivty	Percent Specificity	Percent Agreement	Kappa Statistic†	95% CI‡		
≥2500 normal weight	1534	1554	1529	99.7	80.8	98.2	0.87	0.82, 0.91		
<2500 low weight**	130	110	105	80.8	99.7	98.2	0.87	0.82, 0.91		
<1000 extremely low	13	15	13	100	99.9	99.9	0.93	—		
Birth Weight with ICD-9-CM codes, validation samples†	Registry Sample Birth Weight Categories by ICD-9-CM Codes									Validation Sample totals
	764.x9	764.x8	764.x7	764.x6	764.x5	764.x4	764.x3	764.x2	764.x1	
≥2500, 764.x9	1529	2	0	0	2	0	0	0	1	1534
2000-2499, 764.x8	24	50	0	0	0	0	0	0	0	74
1750-1999, 764.x7	1	0	14	0	0	0	0	0	0	15
1500-1749, 764.x6	0	0	0	10	0	1	0	0	0	11
1250-1499, 764.x5	0	0	0	1	8	0	0	0	0	9
1000-1249, 764.x4	0	0	0	1	0	6	1	0	0	8
750-999, 764.x3	0	0	0	0	0	0	7	0	0	7
500-749, 764.x2	0	0	0	0	0	0	0	6	0	6
<500, 764.x1	0	0	0	0	0	0	0	0	0	0
Registry sample totals	1554	52	14	12	10	7	8	6	1	

CI = confidence interval.

*The sample size for birth-weight comparisons is 1664 because 5 reviewed records lacked birth weight data. All birth weights are in grams.

†P < 0.0001 for all kappa statistics, exact P values computed for extremely low birth weight, 95% CI = 95% confidence interval for the kappa statistic, not included for extremely low birth weight due to small sample size.

**Includes the extremely low birth weight birth records.

‡Registry data from ICD-9-CM fifth digit codes: 764.xx, 765.0x and 765.1x refer to specific weight ranges. On this table 764.xx codes also represent 765.0x and 765.1x codes.

The reviewed validation sample reflects infants captured in the Registry born at MTFs from 1999-2002, with a deliberate oversampling of infants with birth defects. In analyses, kappa statistics indicate "near perfect" agreement for all outcomes assessed between datasets, except for extreme preterm births, where our sample size was small and agreement was only "moderate." In addition, when the threshold for preterm births was lowered from an EGA of <37 weeks, to <36 weeks, the sensitivity increased, specificity decreased, and total agreement and kappa statistics decreased slightly. Researchers often use a more stringent threshold for preterm births in an effort to avoid diagnostic misclassification of infants born near term.^{30,31} This approach, however, is not appropriate for investigations using data derived from ICD-9-CM codes, where diagnoses are classified by EGA and birth-weight ranges. These analyses validate Registry studies using the standard definitions for preterm (<37 weeks) and low-weight births (<2500 grams) knowing that corresponding ICD-9-CM codes accurately reflect medical record data.

Limitations

The primary limitation is that this study compared agreement only for births occurring in MTFs, thus excluding the 40% of Registry births that occurred in civilian facilities, for the years 1999-2002. This study is also limited by the

omission of same-sex multiples from Registry analytical data sets. However, many investigations of preterm and low birth weight are limited to singleton births, which somewhat mitigates this limitation. The Registry will also not account for infants born in DoD hospitals if their military parent leaves the service shortly before or immediately after birth. In these situations, military medical benefits would continue for obstetric care, but would not cover the infant's later medical care. The inability to match infant records could also occur when an infant's identifying information changes, or when changes occur to the "official" military sponsor parent, for dual military parent families, if the change occurred between the date of birth and the date of assignment of an infant's unique medical identification number. These infants would be in the Registry, though, for this study, would not match records based on selected variables. At most, these latter examples represent 18 unmatched infant records from the available records reviewed.

Another limitation is the deliberate oversampling of infants with birth defects in the validation sample. Infants with birth defects are more likely to be preterm, or low birth weight.^{9,10} As a result, these infants require more medical care, as a group, and therefore have more opportunity for ICD-9-CM coding of any preterm or low-weight births. However, these results show no differences in measures

of agreement based on the presence or absence of a birth defect. Another limitation is the military branch of service imbalance in this study, with a slightly higher percentage of Navy family births and a much lower percentage of Air Force family births. Again, there were no measures of agreement differences based on service branch, or hospital specific characteristics between data sources. Nevertheless, this dissimilarity in the composition of the validation sample and the Registry sample deserves noting as there are differences in the military services with respect to racial and ethnic composition of personnel, and the proportions of different military rank and personnel education levels, which are factors shown to influence birth outcomes.^{2,3,32-40}

A final limitation of this study is that the data are from 1999-2002, which largely predates the addition of the fifth digit to ICD-9-CM code 765.2x. In fiscal year 2003, the fifth digit was added to 765.2x to specify EGA week ranges, and it provides a more refined demarcation of preterm birth outcomes. There may be misclassification for EGA due to the use of less specific codes for preterm births for infants born prior to this ICD-9-CM update. Future analyses of preterm birth could reduce this potential bias by limiting the study population to infants born during fiscal year 2003 or later.

Strengths

The principal strength of this investigation is the large number of assessed birth records coming from a geographically diverse selection of MTFs. These records, matched and compared with the Registry sample, provide statistics on the accuracy of ICD-9-CM-derived information in the Registry. Additionally, a weighted adjustment to correct for the high percentage of infants with birth defects in the validation sample suggests that the Registry misclassifies (over-identifies) full-term births by 1.2%, and normal-weight births by 0.26%, for MTF births from 1999-2002 (data not shown). In our sample, the majority of this misclassification occurred among infants between 36 and 37 weeks of gestation, or nearly full-term, and nearly all of the birth-weight misclassification occurred among infants between 2000 and 2499 grams, or nearly normal birth weight. This finding provides the Registry team with specific parameters for conducting sensitivity analyses in other studies involving these birth outcomes.

Conclusion

Public health efforts to improve birth outcomes require surveillance systems that capture population-wide data efficiently and accurately. This specific study improves knowledge on the accuracy and completeness of data capture using ICD-9-CM coding for preterm and low birth weight outcomes in the over 1-million-subject DoD Birth and Infant Health Registry by demonstrating agreement between the Registry and medical record data. Further, it establishes specific misclassification parameters in support of other Registry studies assessing preterm and low birth weight outcomes. These results also provide a measure of validity for investigators that rely on ICD-9-CM code-derived gestational age and birth weight information.

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